

**JULY 2004 – JUNE 2005**

**A Report to the Governor & The Legislature of the State of New Jersey**

**On The Catastrophic Illness in Children Relief Fund Act**



**N.J.S.A. 26:2-148 et seq.**

**1988 – 2005**

**Jon S. Corzine, Governor**

Kevin M. Ryan, Commissioner of Human Services

Jane Schreadley Lorber, Chairperson

# **CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND COMMISSION**

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Honorable Jon S. Corzine  
Governor  
State of New Jersey  
State House  
Trenton, New Jersey 08625

Dear Governor Corzine:

As Chairperson of the Catastrophic Illness in Children Relief Fund Commission, it gives me great pleasure to submit to you, **A Report to the Governor and the Legislature of the State of New Jersey on the Catastrophic Illness in Children Relief Fund Act, July 2004 to June 2005.**

In State Fiscal Year 2005, the Catastrophic Illness in Children Relief Fund Commission approved \$7.4M in grant awards for 277 families. Many of these families were without health care coverage at the time they incurred significant medical expenses for their children. A remarkable 87 percent of awards, however, were approved for families who were insured and were still burdened with catastrophic medical expenses related to the care of their children. The diverse needs of New Jersey families continue to demonstrate the value of this unique financial safety net.

Since the first grant awards were approved in December 1989 through June 2005 more than \$93M was approved for 3,800 families in need.

The Commission continues to provide meaningful relief for families struggling to cope with the financial responsibilities, which accompany a child's significant health problems. We know that you join the Commission in communicating the Program's message to all families that they do not have to bear high out-of-pocket costs of their children's care alone.

With best wishes,

Jane S. Lorber  
Chairperson

## EXECUTIVE SUMMARY

The Catastrophic Illness in Children Relief Fund Commission approved \$7.4M in grant awards for families in need during State Fiscal Year 2005 (SFY05). The Commission has provided meaningful financial relief for New Jersey families since grant awards were first approved in December 1989. Through June 30, 2005, more than \$93M was approved for 3,800 families.

The data on awards approved in SFY05 demonstrates that financial help was available to meet the diverse needs of 277 New Jersey families, with awards ranging from \$280 to \$100,000. The average award per family was \$65,287. Assistance from The Fund provided financial relief for costs associated with 183 diagnoses and conditions. Families received assistance for a wide array of medical problems, from simple fractures to rare genetic syndromes.

Knowing from its experience that any family, regardless of income or insurance status, may be just one illness or accident away from personal and financial hardship, the Commission reached out to families through a comprehensive public information campaign. Working with volunteer parents, community and official agencies, churches, employers, and print and broadcast media, the Commission disseminated program information throughout the state.

Program expenditures were monitored. The Commission's cost savings initiatives through regulatory caps and cost reduction policy yielded savings in excess of \$1.2M. This effort continues a long-standing practice of the Commission to reduce costs, whenever possible, while ensuring a positive impact on the families served.

The Commission looks forward to continuing its service for New Jersey families, making a difference in the lives of the parents and children faced with extraordinary medical debt.

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## ACKNOWLEDGEMENTS

The Catastrophic Illness in Children Relief Fund Commission would like to express its sincere appreciation to all present and former Commission members and to the NJ Department of Human Services for the talent, time, and energy contributed to the development of this report.

The Commission acknowledges the contributions of member designees in SFY05, including: William A.B. Ditto of the NJ Department of Human Services, who serves as Vice-Chairperson; Pauline Lisciotto of the NJ Department of Health and Senior Services; Robert Thompson of the NJ Department of Treasury; and Ellen DeRosa of the NJ Department of Banking and Insurance.

This report was prepared by the State Office of the Catastrophic Illness in Children Relief Fund Commission.

### The Catastrophic Illness in Children Relief Fund

The Catastrophic Illness in Children Relief Fund was established by legislation to provide financial assistance to families whose children have experienced an illness or condition not fully covered by insurance, state or federal program, or any other resource. The Fund is designed to provide a financial safety net for families struggling with a child's previously incurred expenses.

The definition of a catastrophic illness in this program is economic and is measured in terms of the financial consequences of health care expenses on the family, rather than on traditional diagnostic classifications or acuity of illness.

### Eligibility Requirements

A “catastrophic illness” means any illness or condition in which the incurred medical expenses are not covered by any state or federal program, insurance contract, or other resource, and exceeds an established eligibility threshold. In SFY05, a “catastrophic illness” was defined in statute to mean uncovered expenses incurred in the care of a child, which exceeded 10 percent of the first \$100,000 of annual income of a family, plus 15 percent of any excess income over \$100,000. In SFY04, the enabling legislation was amended to expand the age of a “child” to include someone 21 years of age and younger so that The Fund could continue to provide continuity in financial assistance for the young adult population.

The family must be a resident of New Jersey for at least three months prior to submission of an application. Temporary residents, including those coming to this state seeking medical care, are excluded from eligibility with the exception of migrant workers.

Income and expenses are measured for the prior consecutive 12-month period in which the expenses were incurred. The Catastrophic Illness in Children Relief Fund is unique in that it reviews expenses on a retroactive basis. The Fund reviews expenses for a prior consecutive 12-month period of time dating back to 1988 which is the year the statute was enacted. All expenses are reviewed by the Commission and are subject to established caps and program regulations.

### State Significance

A summary of health insurance tables for New Jersey residents for 2003 was released by the New Jersey Department of Health and Senior Services, Center for Health Statistics. The data, derived from the *Current Population Survey: Annual Demographic File, 2003, Bureau of the Census*, estimated that there were 264,129 uninsured children in New Jersey under 19 years of age. This number was reported as 11.5 percent of children in the State.

The Commission has seen that the cost of coverage remains a significant obstacle in access to health insurance for many families in New Jersey. For those families with insurance who applied for assistance, their health coverage was seriously inadequate for the medical needs of the child.

In New Jersey, health insurance is tied to employment for most families. Loss of employment often leads to loss of health benefits. Once a parent no longer has health coverage through a job, the family is often unable to afford the full cost of health premiums. For many parents, loss of employment is a frequent result after long hours away from work caring for a seriously ill child, driving to physician offices, and sitting in hospital rooms. With a struggling economy, jobs are harder to find, and parents are not making a seamless transition to other employment.

Costs for health care are increasing, particularly for hospital, physician, and pharmacy services. Employers are increasingly passing on costs for employee and/or dependent coverage to employees in the form of larger premiums, higher deductibles, and co-payments. The downgrading of benefits by employers continues.

Employers who offer self-funded health plans, including unions, are covered by the federal Employee Retirement Income Security Act of 1974 (ERISA) and may offer insurance coverage which is exempt from state insurance regulation and mandated benefits. These self-funded plans provide more choice for employers in containment of health costs and are increasingly seen in applications to The Fund. Self-funded health plans had previously experienced bankruptcy, indicating that this approach to health coverage can add to the volatility of the insurance marketplace.

Although subsidized health coverage for uninsured children is available through NJ FamilyCare, the federal Children's Health Insurance Program, some families may experience a lapse in coverage when a child may have uncovered medical expenses. The Commission has the ability to fill in these gaps and may provide financial assistance for those families.

Since its inception in 1989, the Commission has filled a need in providing financial relief for families from a wide socio-economic range. A great majority of the families was employed, had some form of insurance, and yet was still vulnerable to personal and financial distress from catastrophic medical costs. Historical data supports that the Commission has approved \$93M to assist 3,800 families with health care and related expenses that were otherwise uncovered by insurance or any other resource, including, but not limited to, state or Federal funds. Remarkably, awards have ranged from \$280 to \$907,585. Family income levels span from \$0 to \$401,243. Significant efforts have been made since The Fund's inception, and will continue to be made, to assure that all New Jersey families are aware of The Fund's existence.

### **Catastrophic Illness in Children Relief Fund Commission**

The Commission is established in, but not of, the New Jersey Department of Human Services (DHS). Within DHS, the State Office of the Commission is administratively assigned in the Office of the Commissioner.

The Commission membership consists of 11 members: four members ex officio and seven members appointed from the public by the Governor with the advice and consent of the Senate for terms of five years. Two of the public members must be providers of health care services for children in this State. The ex officio members are the Commissioners of DHS, the NJ Department of Health and Senior Services (DHSS), the NJ Department of Banking and Insurance (DOBI), and the NJ Department of Treasury.

### **Responsibilities of the State Office of the Commission**

The State Office of the Commission is responsible for administering The Fund on a day-to-day basis and maintaining confidential files on all applicant families. The Fund is operated within the intent and provisions of its statute, program regulations, and compliance with Commission policies and decisions.

Staff in the State Office of the Commission provides guidance needed by the family to initially submit provider bills to insurance, seek Charity Care determinations, or otherwise utilize available resources before submitting an application for financial assistance. Staff provides information for families in utilizing health care services and understanding reimbursement systems.

### **Coordination with Special Child, Adult and Early Intervention Services**

The enacting legislation requires that The Fund work in conjunction with Special Child, Adult and Early Intervention Services (SCAEIS) in DHSS. The Commission has continued its grant to SCAEIS for contracted services from the Special Child Health Services (SCHS) Case Management Units in each county to ensure that families have access to program information and referral at the local level.

### **Public Information**

As part of its mandate, the Commission is required to disseminate information to the public. Through the efforts of the Department's media contract, the Commission was able to publicize its information throughout the entire state. The Commission's Public Information Plan (PIP) is designed to enhance public awareness of The Fund through outreach efforts and paid advertising. The distinct and creative designs, which identify The Fund, continued on all program materials and transit advertising. The unique 800-phone number continued to be available to the public as the Family Information Line, 1-800-335-FUND, which provides easy access to The Fund. The web address was changed to [www.njcatastrophicfund.org](http://www.njcatastrophicfund.org) to provide a more recognizable name which would be easier for families to access and retain.

Other efforts included the Commission's annual press event with Governor Codey who welcomed families who had received an award from the Commission in SFY05 to the State House on December 14, 2004. The Commission's Annual Meeting was held on June 22, 2005 where the Commission joined the Family Advisory Committee (FAC) and guests. The FAC supports the Commission in disseminating program information at the local level. In SFY05, the FAC had 148 active families.

### **Collection and Accounting of the Fund**

In accordance with the provisions of P.L. 1987, C.370, the Commission is responsible for assessing a \$1 annual surcharge per employee for all employers subject to the New Jersey Unemployment Compensation Law, R.S. 43:31-1 et seq. The surcharge is collected to provide revenue to meet the purposes of The Fund. The surcharge is collected by the State Department of Labor and Workforce Development and paid over to the State Treasurer for deposit into The Fund. Interest earned on the money collected is credited to The Fund.



### CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND Fund Balance

	ACTUAL FY04	ACTUAL FY05
<b>REVENUES:</b>		
FUND BALANCE JULY 1	\$13,394,903	\$ 3,836,349
SERVICES AND ASSESSMENTS	\$ 5,340,122	\$ 6,809,299
INVESTMENT EARNINGS	\$ 89,018	\$ 79,830
TRANSFERS FROM OTHER FUNDS(S1348)		\$ 3,000,000
<b>TOTAL REVENUE</b>	<b>\$ 18,824,043</b>	<b>\$13,725,478</b>
<b>EXPENDITURES:</b>		
PHYSICAL AND MENTAL HEALTH	\$ (111,513)	\$ (97,754)
GOV DIRECTION, MANAGEMENT & CONTROL	\$ (6,750,704)	\$ (6,673,858)
OPERATING EXPENSES	\$ (1,125,477)	\$ (1,110,155)
<b>TOTAL EXPENDITURES</b>	<b>\$ (7,987,694)</b>	<b>\$ (7,881,767)</b>
<b>OTHER FINANCIAL USES:</b>		
TRANSFERS TO OTHER FUNDS (HEALTH)	\$ (4,000,000)	
IMPACT OF S1348- LEAD POISONING	\$ (3,000,000)	
<b>TOTAL OTHER FINANCIAL USES</b>	<b>\$ (7,000,000)</b>	<b>\$</b>
<b>TOTAL EXPENDITURES &amp; OTHER FINANCIAL</b>	<b>\$ (14,987,694)</b>	<b>\$ (7,881,767)</b>
<b>FUND BALANCE JUNE 30</b>	<b>\$ 3,836,349</b>	<b>\$ 5,843,711</b>

**Note:** Financial Statements on revenue, expenditures and other financial issues of the Fund were prepared utilizing figures provided by the State Department of Treasury and annotated by fiscal staff of the Catastrophic Illness in Children Relief Fund Commission.

In SFY05, the Commission approved \$7.4M for 277 families. Although ineligible for assistance from the Fund, 26 families were referred for other state resources as appropriate. Twenty-four applications did not meet The Fund's financial eligibility threshold. Two applications were ineligible based on residency. (See Table)

<b>TOTAL AWARDS APPROVED</b>	<b>\$7.4M</b>
<b>TOTAL APPLICATIONS APPROVED</b>	<b>277</b>
Range of Awards	\$280 - \$100,000
Average	\$26,528
Range of Income	\$0 - \$351,499
Average	\$65,287
Average Expense: Income	184 %

Applications reviewed by the Commission reflected a range of uncovered expenses among families in need. Awards approved by the Commission in SFY05 ranged from \$280 - \$100,000. Similarly, the range of expense-to-income threshold was as dramatic as the range in awards. Families meeting eligibility had uncovered expenses between 10 percent and 184 percent of income.

The range in income status of applicant families continues to increase. Families with higher incomes realize that the Fund is a viable resource when uncovered medical expenses become proportionately high for them. (See Chart)

### CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND COMMISSION AWARDS BY INCOME SFY05

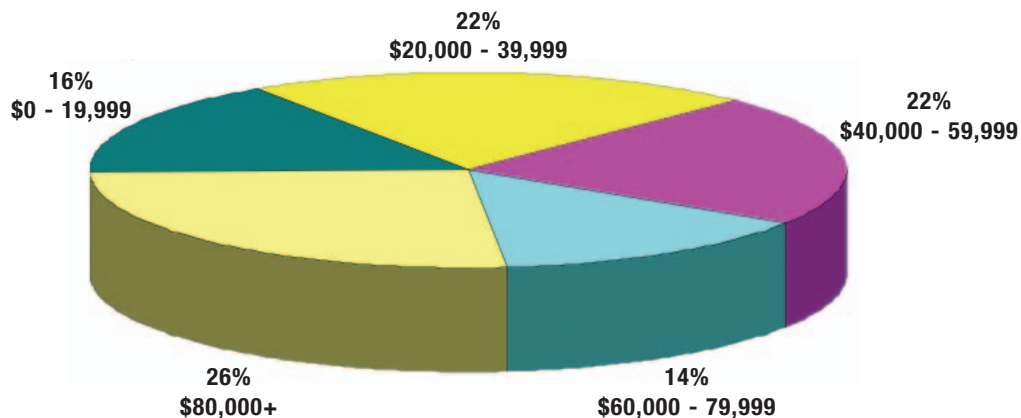


Table 1

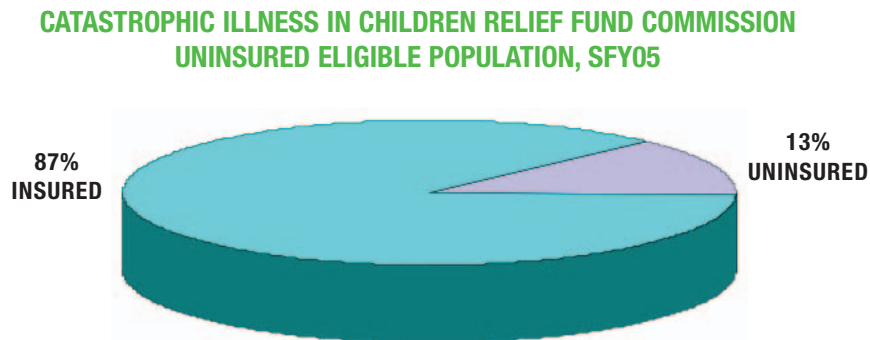
**CATASTROPHIC ILLNESS IN CHILDREN RELIEF FUND COMMISSION  
APPLICATIONS BY COUNTY SFY05**

COUNTY	TOTAL REVIEWED	ELIGIBLE	INELIGIBLE	EXPENSES	COMMISSION APPROVED	FUND DISTRIBUTION
ATLANTIC	5	5	0	133,205	133,205	118,902
BERGEN	33	32	1	1,276,127	891,194	891,194
BURLINGTON	11	11	0	418,933	352,167	313,261
CAMDEN	16	14	2	304,495	304,495	288,971
CAPE MAY	5	4	1	54,669	54,669	54,439
CUMBERLAND	3	2	1	33,937	33,937	26,432
ESSEX	21	18	3	652,171	629,691	580,928
GLOUCESTER	18	15	3	301,440	297,141	293,734
HUDSON	8	7	1	104,036	104,036	104,036
HUNTERDON	5	5	0	488,077	367,447	316,652
MERCER	10	9	1	262,711	262,711	237,905
MIDDLESEX	22	20	2	646,744	646,744	579,17
MONMOUTH	20	18	2	354,645	354,645	342,951
MORRIS	25	24	1	729,222	690,416	657,098
OCEAN	30	28	2	363,230	363,230	350,304
PASSAIC	29	26	3	659,974	611,535	539,202
SALEM	1	0	1	0	0	0
SOMERSET	9	9	0	245,139	245,139	230,680
SUSSEX	8	7	1	135,955	135,955	135,955
UNION	16	16	0	624,580	602,268	572,994
WARREN	8	7	1	350,625	350,625	266,328
TOTALS	303	277	26	\$8,139,915*	\$7,431,250	\$6,901,139*

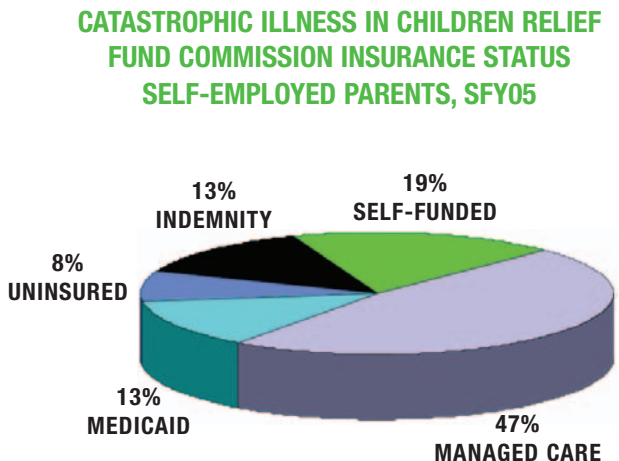
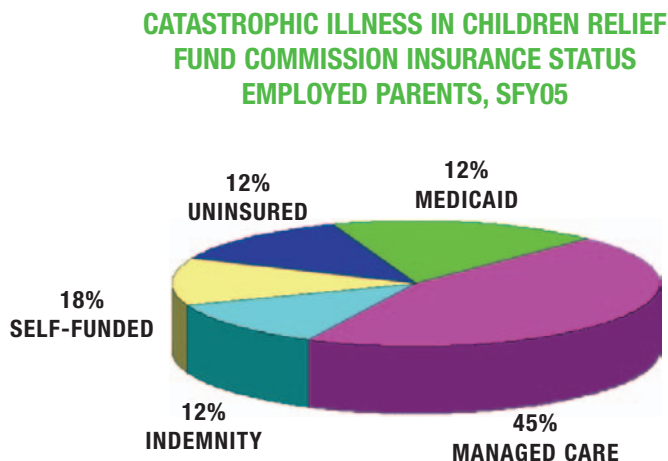
\*Utilization of regulatory caps combined with standardized discounts saved The Fund \$1,200,000 in SFY2005.

### Insurance Status of Eligible Parents, SFY05

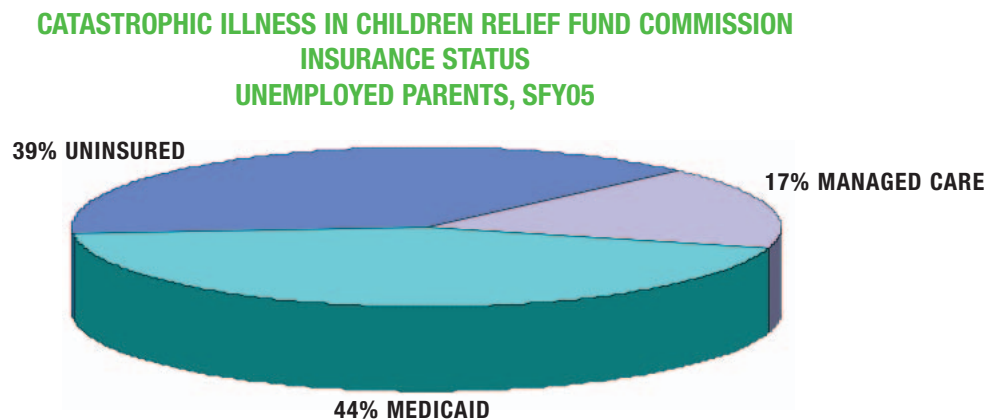
Some form of insurance covered the majority of families eligible for assistance regardless of employment status. More than 87 percent of the families were insured and still had extraordinary out-of-pocket expenses incurred in the care of a child. (See Chart)



An analysis of applications by employment status reflects that the majority of the employed and self-employed parents (n=259) was insured by either private insurance or Medicaid. Of the employed parents (n=221), 12 percent were covered by indemnity plans, 45 percent were covered by managed care, 18 percent were covered by self-funded, and 12 percent whose children were covered by Medicaid. These self-funded plans represent a combination of health plans that are outside the regulatory jurisdiction of DOBI and DHSS. They may include, but are not limited to, trade unions and most self-funded employer groups that have an ERISA exemption, which excludes them from offering the state mandated benefits as part of their insurance plans. Of the self-employed parents (n=38), 13 percent were covered by indemnity plans, 47 percent were covered by managed care, 19 percent were covered by self-funded plans and 13 percent whose children were covered by Medicaid. The uninsured for each group reflects twelve and eight percent, respectively. (See Charts)



The unemployed parents eligible for Fund assistance (n=18) confirms that insurance is connected to employment. Of this group, 17 percent were covered by managed care, none were covered by either indemnity plans or self funded plans, and 44 percent had Medicaid coverage for the child. The uninsured in this group of parents was 39 percent. Some parents, though unemployed, were able to continue insurance through the Consolidated Omnibus Budget Reconciliation Act when it was available and affordable. Others had insurance coverage available only for a short period of time after employment ended. Many were uninsured, as they were unable to purchase insurance directly due to the high cost of self-pay coverage. (See Chart)



Families who continue to be uninsured at the time the Commission reviews an application are referred by the State Office of the Commission to appropriate state agencies for information on available insurance products and government programs. Families who appeared eligible for other programs are referred as well.

### Public Need for the Fund

In SFY05, 277 eligible families sought assistance for uncovered expenses due to a variety of circumstances. Assistance offset expenses for the following general categories:

- <1% Lack preauthorization
- 29% Expenses exceeded charges allowed by insurance
- 80% Non-covered services

In SFY05, 36 families eligible for financial assistance were uninsured. This represents 13 percent of the eligible families. The Commission anticipates a continued demand for The Fund by parents whose expenses were incurred during a break in health insurance coverage.

In SFY05, the Commission reviewed applications for expenses dating back to 1994. It may review expenses dating back to 1988.

### Review of Appeals

In SFY05, the Commission reviewed four appeals and reversed the initial determination of ineligibility for one application based on additional information supplied by the family.

### Review of Withdrawn Applications

This category reflects applications which have been reviewed by staff and have less than five percent of uncovered expenses or lack documentation to determine eligibility. Families may request the application be reopened in the future if they are able to provide additional documentation. This process offers families the opportunity to pursue eligibility again with minimal additional effort. In SFY05, the Commission found eligibility for eight applications that had been previously withdrawn, after families provided the required information.

### Review of Lawsuit Recoveries

The State Office monitors all legal actions and lawsuits reported by families. During this time period, there was no reimbursement to The Fund from settlements of legal actions relating to applications.

### Review of Categories of Eligible Health Services

The Fund considers a broad range of health services, including medical and other services, which may not always be reimbursable under traditional health insurance policies. Additionally, The Fund is unique in that it considers non traditional health expenses such as home modifications and the purchase/lease of a specialized, modified vehicle to accommodate a child's disability and modifications to subsequent vehicles purchased by a family. The Fund does not reimburse for special education services required as a result of medical condition or elective cosmetic surgery.

*Chapter 10:155* identifies the categories of health services that are considered as eligible, which a family may submit for review to the Commission. The following summarizes the unduplicated count of categories of eligible health services considered for payment in applications approved by the Commission in SFY05.

Category of Eligible Health Service	Frequency
Transportation	59 %
Physician Services	53 %
Health Insurance Premium	33 %
Pharmacy	30 %
Specialized Pediatric Ambulatory Care	27 %
Hospital, In State	22 %
Durable Medical Equipment	21 %
Disposable Medical Supplies	19 %
Hospital, Out of State	17 %
Home Modification	16 %
Ancillary Services	9 %
Temporary Shelter	8 %
Home Health Care	5 %
Specialty Hospital, Out of State	3 %
Specialty Hospital, In State	1 %
Funeral Expenses	1 %
Long Term Care	0
Experimental Services	0

### Review of Medical Conditions

Families apply to the Catastrophic Illness in Children Relief Fund for their children's medical expenses, which result from an illness or health related condition. The illness or condition is assigned the appropriate diagnostic code based on Ingenix, Encoder Pro, a web-based service.

Encoder Pro provides the International Classification of Diseases World Health Organization's Ninth Revision, Clinical Modification ICD-9-CM codes and descriptions based on the official U.S. Department of Health and Human Services ICD-9-CM codes effective each current year. ICD-9-CM classifies morbidity and mortality information for statistical purposes, indexing of hospital records by disease and operations, data storage and retrieval. It is designed with precise codes and a classification system that indexes health related conditions, diseases, and procedures, which help describe the clinical picture of the person and is used to classify morbidity data when compiling basic health statistics. The codes can contain up to five digits whenever a greater specificity of a diagnosis is required.

The ICD-9-CM is based on the official version of the Ninth Revision, International Classification of Disease (ICD-9).

The following is an unduplicated list of diagnoses and conditions presented to the Commission in SFY05. The list is comprised of both physical and mental health diagnoses, which have generated medical expenses, deemed eligible by the Catastrophic Illness in Children Relief Fund Commission.

### Catastrophic Illness in Children Relief Fund Commission Unduplicated List of Diagnoses/Conditions In SFY05 Eligible Applications

Diagnosis (N=142)	Code	Diagnosis (N=142)	Code
Acute Appendicitis	540	Dental Caries	521
Acute Lymphoid Leukemia	204	Dentofacial Anomalies, Including Malocclusion	524
Adjustment Reaction	309	Depression	311
Adjustment Reaction With Anxious Mood Disorder	309.24	Developmental Delay	783.4
Agenesis of Corpus Callosum	742.2	Diabetes Mellitus	250
Amblyopia, Unspecified	368	Disorders Of The Pituitary Gland And Its Hypothalamic Control	253
Anomalies of Cerebrovascular System	747.81	Down's Syndrome	758
Anomalies of Diaphragm	756.6	Duchenne Muscular Dystrophy	359.1
Anomalies of Skull and Face Bones	756	Dysphagia	787.2
Anorexia Nervosa	307.1	Encephalopathy	348.3
Anoxic Brain Damage	348.1	Epidermolysis Bullosa	757.39
Apnea	786.03	Epilepsy	345.9
Appendicitis	541	Esotropia	378
Appendicitis with Perforation	540	Extreme Immaturity	765
Appendicitis Without Mention of Peritonitis	540.9	Familial Dysautonomia	742.8
Apraxia	784.69	Fracture of Vertebral Column with Spinal Cord Injury	806.25
Acrocephalosyndactyly (Apert's Syndrome)	755.5	Friedreich's Ataxia	334
Arthrogryposis	728.3	Gastroesophageal Reflux	530.1
Arthrogryposis Multiplex Congenita	754.89	General Convulsive Epilepsy	345.1
Asthma	493	Geroderma Osteodysplastica	756.8
Atrial Septal Defect	745.5	Hearing Loss	389.9
Attention Deficit Hyperactivity Disorder	314.01	Hemiplegia	342.9
Autism	299	Hirschsprung's Disease	751.3
Bronchiectasis	494	Hydrocephalus, Communicating	331.3
Bronchopulmonary Dysplasia	770.7	Hydrocephalus, Congenital	741
Bulimia	307.51	Hypoplastic Left Heart Syndrome	746.7
Central Core Myopathy	359	Hypotonia	781.3
Cerebral Laceration and Contusion	851	Infection Due to Vascular Device, Implant, or Graft	996.62
Cerebral Palsy	343.9	Infection Specific to Neonatal Period	771.8
Chronic Sinusitis	473.9	Inguinal Hernia	550
Chronic Sinusitis, Ethmoidal	473.2	Interruption of Aortic Arch	747.11
Cleft Palate with Cleft Lip	749.2	Intraventricular Hemorrhage	772.1
Coarctation of the Aorta	747.1	Kyphosis	737.3



Congenital Hereditary Muscular Dystrophy	359	Late Effects of Burns, Unspecified Sites	906.8
Congenital Hydrocephalus	742.3	Lymphangioma	228.1
Congestive Heart Failure	428	Major Depression, Recurrent	296.3
Convulsions	780.39	Malignant Neoplasm of Brain	191
Cortical Blindness	377.75	Malignant Neoplasm of Other Endocrine Glands and Related Structures	194
Microcephaly	742.1	Malignant Neoplasm Without Specification of Site	199
Mitochondrial Myopathy	359.9	Malignant Neoplasm, Long Bones of Lower Limbs	170.7
Multiple Congenital Anomalies	759.7	Malocclusion, unspecified	524.4
Muscular Dystrophy, Hereditary Progressive	359.1	Mental Retardation	318
Myoclonus	333.2	Septo-Optic Dysplasia	743.1
Myopathy, unspecified	359.9	Sickle Cell Anemia	282.6
Myotonic Dystrophy	359.2	Spina Bifida with Hydrocephalus	741
Neonatal Hypoglycemia	775.6	Spina Bifida without Mention of Hydrocephalus	741.9
Neoplasm of Brain	239.6	Spinal Muscular Atrophy	335.1
Neoplasm, Connective Tissue	171.9	Strabismus	378.9
Nephrotic Syndrome	581.9	Syncope and Collapse	780.2
Non-Hodgkin's Lymphoma	202.8	Tetralogy of Fallot	745.2
Noninfectious Gastroenteritis and Colitis	558.9	Thrombocytopenia, unspecified	287.5
Obstructive Hydrocephalus	331.4	Toxic Effects of Lead and its Compounds (Including Fumes)	984
Osteochondritis Dissecans	732.7	Transposition of Great Vessels	745.1
Osteogenesis Imperfecta	756.51	Transverse Myelitis	323.9
Osteogenic Sarcoma	170.7	Unspecified Transient Organic Mental Disorder	293.9
Other Chromosomal Abnormalities	758.8	Urinary Tract Infection	599
Other Diseases of Trachea and Bronchus Not Elsewhere Classified	519.1	Ventricular Septal Defect	745.4
Other Fractures of Distal End of Radius	813.42	Viral Pneumonia	480
Other Lymphomas	202.8	Visual Impairment, Both Eyes	369
Other Speech Disturbances	784.5	Werdnig Hoffman Disease	335
Other Symbolic Dysfunction	784.6	Respiratory Distress Syndrome	769
Paraplegia	334.1	Respiratory Failure	518.81
Pervasive Developmental Disorder	299	Respiratory Problems in Newborn	770.8
Other Specified Pervasive Developmental Disorders, Asperger's Disorder	299.8	Retrolental Fibroplasia	362.21
Pneumonia	486	Rett Syndrome	330.8
Post Traumatic Stress Disorder	309.81	Schizencephaly	742.4
Prematurity	765.1	Scoliosis	737.3
Primary Pulmonary Hypertension	416	Secondary Cardiomyopathy, Unspecified	425.9
Primary Thrombocytopenia	287.3	Seizure Disorder	780.3
Pulmonary Artery Stenosis	747.3	Sensorineural Hearing Loss	389.1
Pulmonary Insufficiency Following Surgery	518.5	Pulpitis	522

#### Fiscal Issues

Faced with diminishing reserves, the Commission previously realized that it had to ensure resources were available for families applying for financial assistance. Prior legislative diversions contributed to utilizing The Fund's surplus. One measure implemented at the end of SFY04 and continued throughout SFY05 was the utilization of the annual \$100,000 cap for each application. Staff was able to successfully negotiate discounts on all large balance accounts, and families were held harmless from these balances. Implementation of this regulatory provision along with the combined practice of a standardized discount approach to accounts in excess of \$10,000 realized savings in excess of \$1.2M in SFY05. (See Table 1, page 11) In the last ten years, the discount policy realized savings in excess of \$10M.

Looking forward, the Commission realized that additional, on-going fiscal support was necessary to ensure the longevity of The Fund since prior legislation increased the age of a child to include the young adult population. Although the enabling statute was amended previously to allow more families to apply, the funding mechanism remained constant. With a growing population, high costs of health care and technology, Commission expenditures would continue to rise. The annual revenue would not be able to support The Fund activity. The Commission voted to support new legislation that would increase the assessment from \$1 per employee to \$1.50. Based on projections, this increase would result in additional \$2.9M annual revenue. The increase would ensure that the Commission could support its requests for assistance and not operate at a deficit. Support from the legislature and administrative officials indicated that the Commission should continue to provide the same level of benefits. The \$1.50 fee increase supports this concern and at the same time, does not jeopardize the integrity of The Fund.

#### Public Information Efforts

Historically, the Commission has realized that without an ongoing, active, multi-media campaign, The Fund would not be able to reach its potential population of applicant families. Fortunately, in SFY05, the Commission was able to piggyback on the DHS advertising contract. With a defined public information plan in place, the Commission reached many audiences through a variety of endeavors. In SFY05, application requests increased which is attributable to the aggressive public information activities. Through the contract, the Commission reached more people which was necessary due to the age expansion. An additional 22 applications were received in SFY05 compared to SFY04. Additionally, the Commission provided assistance to nine families whose children benefited from the age expansion legislation.

Through the efforts of the FAC, the public service announcement (PSA) was revised and several families who had received assistance from The Fund participated in this project. This PSA airs on NJN Public Television. Other families opened their homes to television crews to film a spot on "Prime Time Saturday," which aired on WPVI Channel 6. Additionally, a Hispanic family agreed to be interviewed in their home by Channel 47, Telemundo. This was an important opportunity to reach out to the Hispanic population, made possible by the generosity of a recipient family. All of these media activities reached many residences and calls for applications immediately followed the airing of each media spot.

#### Testimonials

Families from all economic backgrounds applied for assistance and were extremely grateful for their financial support. The following testimonials from recipient families validate the success and effectiveness of The Fund.

*“I wanted to take this opportunity to say thank you, although I am finding it difficult to find the perfect words to express our sincere gratitude. I do not think there are the perfect words to express this overwhelming feeling of relief, hope and love that you have given us. We felt like we were drowning until we contacted you. You have saved us and we will be forever grateful.”* (Middlesex County, Parent of 4 year old)

*“Thank you for everything you have done for our family. I will never be able to thank you all enough... for what the Catastrophic Fund has done for my son and for my family... you gave us the ability to make our son our priority. Thank you again from the bottom of my heart.”* (Somerset County, Parent of 3 year old)

*“We would like to thank you for your generosity in rewarding us with this wonderful grant from your organization. We feel so honored and excited to receive your help in this matter. We greatly appreciate what you have done for us and are pleased to know that there organizations such as yours that are dedicated to helping people with such problems. We thank you from the bottom of our hearts.”* (Sussex County, Parent of 10 year old)

*“Thank you all for your review and approval and attention to our application and distribution. It meant everything to us... thank you so very much.”* (Burlington County, Parent of 8 year old)

*“Thank you very much for helping our family. We are stronger because of you!”* (Camden County, Parent of 1 year old)

#### Conclusion

Any family in New Jersey may find needed financial assistance from the Catastrophic Illness in Children Relief Fund if their child's uncovered medical expenses have become catastrophic for that family. Because The Fund assists such a broad segment of the population, it is not possible to focus on a limited audience for dissemination of public information. Rather, it is necessary to identify a variety of target audiences involved with children and to diversify advertising efforts as efficiently and cost effectively as possible in order to reach those audiences statewide.

The public needs program information to be available directly as well as through traditional sources of information, such as: health care providers, state, and community organizations. The Commission's PIP in SFY05 provided for such dissemination of information.

Combined efforts by the Commission, staff, FAC volunteer parents and advertising vendors provided the public with access to information on the valuable state resource of the Catastrophic Illness in Children Relief Fund. With an active PIP in place, the Commission is committed to publicizing to its expanded population.

**26:2-148. Findings, declarations**

The Legislature finds and declares that:

a. Although the majority of Americans are covered by some form of health insurance, families nevertheless lack protection against the high cost of chronic or single episodes of serious illness that may destroy their resources. An illness resulting in this potentially devastating financial consequence is referred to as a catastrophic illness.

b. Catastrophic illnesses often threaten to push some families into bankruptcy and others toward seeking inferior medical care and present a major problem for this nation's health care system in that catastrophic illnesses account for over 20% of this nation's health expenditures.

c. The impact of catastrophic illnesses on the family is especially acute in that children have the highest average medical costs among the population as a whole.

d. It is the public policy of this State that each child of this State should have access to quality health care and adequate protection against the extraordinarily high costs of health care services which are determined to be catastrophic and severely impact upon a child and his family.

e. To this end, it is incumbent upon the State to provide assistance to children and their families whose medical expenses extend beyond the families' available resources.

L. 1987,c.370, §1, eff. Jan.7, 1988.

**26:2-149. Definitions relative to catastrophic illness in children**

As used in this act:

a. "Catastrophic illness" means any illness or condition the medical expenses of which are not covered by any other State or federal program or any insurance contract and exceed 10% of the first \$100,000 of annual income of a family plus 15% of the excess income over \$100,000.

b. "Child" means a person 21 years of age and under.

c. "Commission" means the Catastrophic Illness in Children Relief Fund Commission.

d. "Family" means a child and the child's parent, parents or legal guardian, as the case may be, who is legally responsible for the child's medical expenses.

e. "Fund" means the Catastrophic Illness in Children Relief Fund.

f. "Income" means all income, from whatever source derived, actually received by a family.

g. "Resident" means a person legally domiciled within the State for a period of three months immediately preceding the date of application for inclusion in the program. Mere seasonal or temporary residence within the State, of whatever duration, does not constitute domicile. Absence from this State for a period of 12 months or more is prima

facie evidence of abandonment of domicile. The burden of establishing legal domicile within the State is upon the parent or legal guardian of a child.

L.1987,c.370,s.2; amended 1993, c.103, s.1; 1998, c.143, s.1; 2003, c.260, s.1.

#### **26:2-150. Catastrophic Illness in Children Relief Fund**

The "Catastrophic Illness in Children Relief Fund" is established as a nonlapsing, revolving fund. The fund shall be administered by the commission, and shall be credited with monies received pursuant to section 10 of this act.

The State Treasurer is the custodian of the fund and all disbursements from the fund shall be made by the treasurer upon vouchers signed by the chairman of the commission. The monies in the fund shall be invested and reinvested by the Director of the Division of Investment in the Department of the Treasury as are other trust funds in the custody of the State Treasurer in the manner provided by law. Interest received on the monies in the fund shall be credited to the fund.

L. 1987,c.370.

#### **26:2-151. Catastrophic Illness in Children Relief Fund Commission**

There is established in, but not of, the State Department of Human Services the Catastrophic Illness in Children Relief Fund Commission. The commission shall consist of the Commissioner of the State Department of Health and Senior Services, the Commissioner of the Department of Human Services, the Commissioner of the Department of Banking and Insurance, and the State Treasurer, who shall be members ex officio, and seven public members who are residents of this State, appointed by the Governor with the advice and consent of the Senate for terms of five years, two of whom are appointed upon the recommendation of the President of the Senate, one of whom is a provider of health care services to children in this State and two of whom are appointed upon the recommendation of the Speaker of the General Assembly, one of whom is a provider of health care services to children in this State. The five public members first appointed by the Governor shall serve for terms of one, two, three, four and five years, respectively.

Each member shall hold office for the term of his appointment and until his successor has been appointed and qualified. A member of the commission is eligible for reappointment.

Each ex officio member of the commission may designate an officer or employee of his department to represent him at meetings of the commission, and each designee may lawfully vote and otherwise act on behalf of the member for whom he constitutes the designee. Any designation shall be in writing delivered to the commission and filed with the office of the Secretary of State and shall continue in effect until revoked or amended in the same manner as provided for designation.

L.1987,c.370,s.4; amended 1993, c.103, s.2; 1994, c.149, s.1; 1998, c.143, s.2.

#### **26:2-152. Suspension; oaths; vacancies**

Each member of the commission may be removed from office by the Governor, for cause, after a public hearing and may be suspended by the Governor pending the completion of the hearing. Each member of the commission before

entering upon his duties shall take and subscribe an oath to perform the duties of his office faithfully, impartially and justly to the best of his ability. A record of the oaths shall be filed in the office of the Secretary of State.

Any vacancies in the membership of the commission occurring other than by the expiration of a term shall be filled in the same manner as the original appointment, but for the unexpired term only.

L. 1987,c.370.

**26:2-153. Commission; Officers; voting; compensation; time for appointment and organization**

The members shall elect a chairperson and chief executive officer of the commission who shall be one of the public members of the commission. The commission shall by rule determine the term of office of the chairperson and chief executive officer. The members shall elect a secretary and a treasurer who need not be members of the commission and the same person may be elected to serve both as secretary and treasurer.

The powers of the commission are vested in the members thereof in office from time to time and six members of the commission shall constitute a quorum at any meeting thereof. Action may be taken and motions and resolutions adopted by the commission at any meeting thereof by the affirmative vote of at least six members of the commission. A vacancy in the membership of the commission shall not impair the right of a quorum to exercise all the powers and perform all the duties of the commission.

The members of the commission shall serve without compensation, but the commission shall reimburse its members for the reasonable expenses incurred in the performance of their duties based upon the monies available in the fund.

The commission shall be appointed within three months after the effective date of this act and shall organize as soon as may be practicable after the appointment of its members.

L.1987,c.370,s.6; amended L.1994,c.149,s.2.

**26:2-154. Powers and duties of commission**

The commission has, but is not limited to, the following powers and duties:

a. Establish in conjunction with the Special Child Health Services program established pursuant to P.L.1948, c.444 (C.26:1A-2 et seq.) a program for the purposes of this act, administer the fund and authorize the payment or reimbursement of the medical expenses of children with catastrophic illnesses;

b. Establish procedures for application to the program, determining the eligibility for the payment or reimbursement of medical expenses for each child, and processing fund awards and appeals. The commission shall also establish procedures to provide that, in the case of an illness or condition for which the family, after receiving assistance pursuant to this act, recovers damages for the child's medical expenses pursuant to a settlement or judgment in a legal action, the family shall reimburse the fund for the amount of assistance received, or that portion thereof covered by the amount of the damages less the expense of recovery;

c. Establish the amount of reimbursement for the medical expenses of each child using a sliding fee scale based on a family's ability to pay for medical expenses which takes into account family size, family income and assets and family medical expenses and adjust the financial eligibility criteria established pursuant to subsection a. of section 2 of this act based upon the moneys available in the fund;

d. Disseminate information on the fund and the program to the public;

e. Adopt bylaws for the regulation of its affairs and the conduct of its business, adopt an official seal and alter the same at pleasure, maintain an office at the place within the State as it may designate, and sue and be sued in its own name;

f. Appoint, retain or employ staff, experts or consultants on a contract basis or otherwise, who are deemed necessary, and employ investigators or other professionally qualified personnel who may be in the noncompetitive division of the career service of the Civil Service, and as may be within the limits of funds appropriated or otherwise made available to it for its purposes;

g. Maintain confidential records on each child who applies for assistance under the fund;

h. Do all other acts and things necessary or convenient to carry out the purposes of this act; and

i. Adopt rules and regulations in accordance with the "Administrative Procedure Act," P.L.1968, c.410 (C.52:14B-1 et seq.) necessary to effectuate the purposes of this act.

L.1987,c.370,s.7; amended 1998, c.143, s.3, 2003, c.260, s.2.

#### **26:2-154-1. Settlement of claims; disposition of recovered moneys**

3. The commission is authorized to negotiate or settle a claim that the fund maintains for reimbursement against a family who has received assistance for the medical expenses of a child with a catastrophic illness pursuant to P.L.1987, c.370 (C.26:2-148 et seq.) and has recovered damages in a legal action for the child's medical expenses. Money recovered pursuant to this section shall be deposited in the fund.

L.1993,c.103.s.3.

#### **26:2-155. Children eligibility to enroll in program**

8. A child who is a resident of this State is eligible, through his parent or legal guardian, to apply to the program established pursuant to subsection a. of section 7 of this act.

L.1987,c.370,s.8; amended 1998, c.143, s.4.

#### **26:2-156. Financial assistance; eligibility; included payments**

9. Whenever a child has a catastrophic illness and is eligible for the program, the child, through his parent or legal guardian, shall receive financial assistance from monies in the fund subject to the rules and regulations established by

the commission and the availability of monies in the fund. The financial assistance shall include, but is not limited to, payments or reimbursements for the cost of medical treatment, hospital care, drugs, nursing care and physician services.

L.1987,c.370,s.9; amended 1998, c.143, s.5, 2003, c.260, s.3.

#### **26:2-157. Funding; annual per person surcharge on individual and group health insurance policies**

For the purpose of providing the moneys necessary to establish and meet the purposes of the fund, the commission shall establish a \$1.00 annual surcharge per employee for all employers who are subject to the New Jersey "Unemployment Compensation Law," R.S. 43:21-1 et seq. The surcharge shall be collected by the controller for the New Jersey Unemployment Compensation Fund and paid over to the State Treasurer for deposit in the fund annually as provided by the commission.

L. 1987,c.370.

#### **26:2-158. Rules and regulations**

The State Treasurer shall adopt rules and regulations in accordance with the "Administrative Procedure Act," P.L.1968, c. 410 (C. 52:14B-1 et seq.) establishing procedures for the collection of the surcharge.

L. 1987,c.370.

#### **26:2-159. Annual reports**

12. The commission shall report annually to the Governor and to each Senate and General Assembly committee with responsibility for issues affecting children, health and human services on the status of the program. The report shall include information about the number of participants in the program, average expenditures per participant, the nature and type of catastrophic illnesses for which the fund provided financial assistance, and the average income and expenditures of families who received financial assistance under the program. The commission also may make recommendations for changes in the law and regulations governing the fund.

L.1987,c.370,s.12; amended 1998, c.143, s.6.



**§ 10:155-1.1 Purpose and scope**

(a) The purpose of this subchapter is to establish criteria for eligibility and establish a standard methodology for determining the amount of financial assistance to be allocated for services of a child's health providers and vendors for families in the State of New Jersey whose child suffers from a catastrophic illness.

(b) The procedures established shall be followed by the Catastrophic Illness in Children Relief Fund Commission.

**§ 10:155-1.2 Definitions**

The following words and terms, as used in this subchapter, shall have the following meanings, unless the context clearly indicates otherwise.

"Act" means P.L. 1987, Chapter 370, N.J.S.A. 26:2-148 et seq. which establishes the Catastrophic Illness in Children Relief Fund.

"Batch" means a grouping of applications for the purpose of applying the provisions of N.J.A.C. 10:155-1.6, 1.7 and 1.8.

"Catastrophic Fund" or "Fund" means the Catastrophic Illness in Children Relief Fund.

"Catastrophic illness" means any illness or condition for which the incurred medical expenses not covered by any other State or Federal program or any other insurance contract or trust which allows funds to provide for the medically related needs of a child as defined in N.J.A.C. 10:155-1.14 or settlement relative to the medical condition of a child exceed 10 percent of the first \$ 100,000 of annual income of a family plus 15 percent of the excess income over \$ 100,000.

"Chairperson" means the chief executive officer of the Commission who is elected by the Commission membership from the public members for a term of one year.

"Child" means a person 21 years of age and under.

"Commission" means the 11 member Catastrophic Illness in Children Relief Fund Commission created by the Act and appointed by the Governor to administer the Fund. The Commission, chaired by a public member, is "in but not of" the Department of Human Services.

"Days" means calendar days.

"Eligibility standard" means that dollar amount greater than 10 percent of the first \$ 100,000 of annual income of a family plus 15 percent of the excess income over \$ 100,000.

"Executive director" means the professional employed by the Commission, in accordance with NJ Department of Personnel's procedures, to administer the Fund on a day-to-day basis on behalf of the Commission.

"Family" means a child and the child's parent, parents, or legal guardian, as the case may be, who is legally responsible for the child's medical expenses.

"Family responsibility" means the amount equal to 10 percent of the eligibility standard.

"Health insurance" means contracts, excluding automobile insurance contracts, whereby an insurer is obligated to pay or allow a benefit for the child as a named insured due to bodily injury, disablement, sickness, or because of any expense relating thereto or because of expense incurred in the prevention of sickness to include limited scope plans such as dental, vision, and prescription drug.

"Income" means the following:

1. Wages before deductions;
2. Public Assistance;
3. Social Security Benefits;
4. Supplemental Security Income;
5. Unemployment and Workman's Compensation;
6. Strike Benefits from Union Funds;
7. Veteran's Benefits;
8. Training Stipends;
9. Alimony;
10. Child Support;
11. Military Family Allotment;
12. Regular Support from Absent Family Member;
13. Pension Payments;
14. Insurance or Annuity Payments;
15. Income from Estates and Trusts;
16. Dividends;
17. Interest Income;
18. Rental Income;
19. Royalties; and
20. Other sources of income not mentioned above; however,

21. Income does not include the following money receipts: withdrawals from a bank; sale of property, house or car; tax refunds; gifts; one-time insurance payments; or compensation from injury, unless the injury directly relates to a child's condition which is the basis for an application being made to the Fund. Also disregarded is non-cash income and any money raised by fundraising.

"Local agency" means the agency responsible for assisting families in the application process, forwarding applications to the State Office, and making appropriate referrals to other state programs and benefits.

"State Office of Catastrophic Illness in Children Relief Fund (State Office)" means the Office of the Executive Director of the Fund, which has responsibility for administering the Fund on a day-to-day basis on behalf of the Commission.

"Threshold" means the point at which a child's out-of-pocket medical expenses exceed 10 percent of the first \$100,000 of annual income of a family plus 15 percent of the excess income over \$ 100,000. After the child's medical expenses reach this threshold, a child has passed the initial screen for eligibility for assistance from the Fund.

**§ 10:155-1.3 General requirements**

(a) Pursuant to the Act, the Fund will provide assistance to families having a child with a catastrophic illness. A child shall have passed the initial screen for eligibility for the Fund's assistance when a child's incurred and verified medical expenses as specified in this chapter for a prior consecutive 12-month period exceed the amount represented by 10 percent of the first \$ 100,000 of verified annual income of a family plus 15 percent of the excess income over \$ 100,000.

1. Ten percent shall be the screen used for families whose income is \$ 100,000 or less.

2. Ten percent of the first \$ 100,000 of annual income of a family plus 15 percent of the excess income over \$ 100,000 shall be the screen used for families whose income is more than \$ 100,000.

(b) Though the child shall be referred to as being eligible at the point in the application process when the child has passed the initial screen, actual Fund disbursements on behalf of a child shall be limited by the monies available in the Fund and shall be guided by the policies and procedures outlined in the subchapter.

(c) To be eligible for assistance, a child must be a resident of the State of New Jersey. Resident means a person legally domiciled in New Jersey for a period of three months immediately preceding the initial date of application for assistance to the Fund.

1. A child's state of residence is that of the parent(s) or legal guardian.

2. Establishing proof of legal domicile within New Jersey is a responsibility of the parent or legal guardian of a child.

3. Absence from New Jersey for a period of 12 months or more is prima facie evidence of abandonment of domicile.

4. Seasonal residents in New Jersey are excluded from eligibility. Seasonal or temporary residence within the State, of whatever duration, does not constitute domicile. Migrant workers who can document a previous history of work in New Jersey are eligible for consideration.

**§ 10:155-1.4 Initial application process**

Applications may be submitted on a year-round basis to the local agency. The name, address, and phone number for the local agencies shall be available from the State Office. The local agency shall forward written applications on forms provided by the State Office for those children who have applied to the State Office.

**§ 10:155-1.5 State Office and Commission review process**

(a) Upon receipt of the application from the local agency, the State Office shall consider the providers' and vendors' charges submitted.

(b) Providers shall be able to demonstrate licensure or certification by appropriate State or Federal agencies, if requested by State Office.

(c) Prior to the Commission's batched review of applications, the State Office shall prepare a disbursement schedule for each application in accordance with N.J.A.C. 10:155-1.6, 1.7 and 1.8.

(d) In a cycle of batch reviews, the Commission shall review the applications and the State Office's disbursement schedule for each application based on the annual cap and the sliding payment schedule and make a decision on the Fund's level of assistance for each case. The calendar for the batch reviews shall be made available to the public by the State Office in advance of each year.

#### **§ 10:155-1.6 Eligibility standard**

Incurred, out-of-pocket medical expenses greater than 10 percent of the first \$ 100,000 of annual income for a family plus 15 percent of the excess income over \$ 100,000 threshold shall be required for eligibility consideration. Those expenses above the family responsibility and up to the cap shall be considered for reimbursement after the eligibility standard is determined and met (see examples in Appendix I).

#### **§ 10:155-1.7 Annual cap and vehicle allowance; home modification allowance; speech, language and hearing allowance**

a) The amount of Fund's disbursements on behalf of a child shall be capped at \$100,000 per year.

(b) A one-time vehicle allowance will be capped at \$ 15,000 for the purchase of a lease or a specialized vehicle. The allowance does not include modifications, which can be considered separately. The one-time vehicle allowance of \$ 15,000 shall be included in the total disbursement cap, in the year the vehicle allowance was disbursed.

(c) The amount of the home modification allowance shall be capped at \$ 25,000 per year.

(d) The amount of the speech, language and hearing services allowance shall be capped at \$ 3,000 per year.

#### **§ 10:155-1.8 Sliding payment schedule**

If adequate funds do not exist in the Fund at the point in time when a particular batch is being considered by the Commission to pay all applicants the amount of their expenses below the annual cap, a sliding payment schedule shall be used in an effort to distribute the available monies to applicants in an equitable way that considers a family's income, assets and other factors which impact the ability to pay for care.

#### **§ 10:155-1.9 Allocation distribution plan**

Because the Fund's actual level of assistance to families, as determined by the Commission, shall in most, if not all, cases be less than the child's medical expenses, the Commission shall determine how the Fund's available monies shall be distributed among eligible providers and vendors. Input from the family shall be sought in the analysis preceding this determination, with guidance from the State Office.

#### **§ 10:155-1.10 Local agency responsibilities**

The local agency shall make referrals and assist in the application process for other programs and benefits (for example, Medicaid, Hospital Charity Care, and other programs), where applicable.

#### **§ 10:155-1.11 State office responsibilities**

(a) The State office shall:

1. Screen applications to determine whether a child's eligible medical expenses exceed 10 percent of the first \$ 100,000 of annual income of a family plus 15 percent of the excess income over \$ 100,000;
2. Maintain oversight to the local agency responsible for assisting families with Program, accepting applications and providing local outreach/information;
3. Administer the Fund on a day-to-day basis on behalf of the Commission;
4. Monitor providers eligibility (that is, certification or other credentials);
5. Consider the reasonableness of providers and vendor charges;
6. Prepare applications for review and consideration of the Commission; and
7. Oversee payments to providers, vendors and, in some cases, to families.

#### **§ 10:155-1.12 Commission responsibilities**

(a) The Catastrophic Illness in Children Relief Fund Commission shall be responsible to:

1. Develop policies and procedures for operation of the Fund;
2. Meet to review and make decisions on applications of families for financial assistance in regularly scheduled cycles; and
3. Negotiate or settle the recovery of funds disbursed in accordance with the provisions of this chapter.

#### **§ 10:155-1.13 Time period for measuring expenses and income**

In screening a child/family for eligibility for the Fund, expenses and income shall be measured by any prior consecutive 12-month time period. The income will be reported for the same prior consecutive 12-month time period back to January 1988. In addition, a supplemental statement of income and expenses may be submitted at the request of the State Office. Applications shall be accepted any time throughout the year.

#### **§ 10:155-1.14 Eligible health services**

(a) Categories of incurred health expenses which are medically-authorized in the care of a child with an illness or condition eligible for consideration is assessing whether a family has reached its eligibility threshold of exceeding 10 percent of the first \$ 100,000 of annual income of a family plus exceeding 15 percent of the excess income over \$ 100,000 include, but are not limited to, the following:

1. Physician-authorized ancillaries (labs, x-rays);

2. Specialized pediatric ambulatory care, including physician-authorized rehabilitative therapies (for example, speech, occupational, and physical), physician-authorized care for treatment of addiction disorders and mental health care, dental care, eye care, chiropractic care;
  3. Care in an acute hospital in New Jersey (treatment for acute and chronic conditions and treatment of addiction disorders and mental health conditions);
  4. Care in acute hospitals in other states (treatment for acute and chronic conditions, and treatment of addiction disorders and mental health conditions as well as highly specialized care such as organ transplants);
  5. Physicians and nursing services in all settings, including primary care (preventive care) and immunization services (for example, office, hospital);
  6. Care in specialty hospitals (for example, rehabilitative, psychiatric);
  7. Long term care (respite care, hospice care, residential care, or other care);
  8. Home health care (physician-authorized home health aide, physician-authorized public health nurse, physician-authorized private duty nurse or other care);
  9. Pharmaceuticals (physician-authorized Federal Drug Administration approved over-the-counter and prescription drugs related to the medical condition and physician-authorized Federal Drug Administration approved medical formulas);
  10. Disposable medical supplies (physician-authorized over-the-counter and prescribed supplies);
  11. Durable medical equipment (for example, physician-authorized ventilators, prostheses);
  12. Home modification that is related to the medical condition of the child at the time the expenses were incurred;
  13. Purchase of a specialized leased or specialized, modified vehicle and any subsequent modifications that are related to the medical condition of the child at the time the expenses were incurred; and
  14. Experimental medical treatment/experimental drugs which are recognized by Federal or State agencies and provided by licensed health care providers. Applications involving experimental treatment/experimental drugs may require additional review.
- (b) Categories of incurred health-related expenses are eligible for consideration in assessing whether a family has reached its eligibility threshold of exceeding 10 percent of the first \$ 100,000 of annual income of a family plus exceeding 15 percent of the excess income over \$ 100,000 include:

1. Family transportation and travel-related expenses including, but not limited to, mileage allowance, tolls, parking receipts, temporary shelter costs and telephone calls related to medical condition.

(c) Fifty percent of a health insurance premium including supplemental and dependent coverage that is paid by a family, not to exceed 50 percent of total eligible expenses, when accompanied by eligible expenses in (a) or (b) above.

#### **§ 10:155-1.15 Ineligible health services**

(a) Categories of health and health-related expenses which are not eligible for consideration in assessing whether a family has reached its eligibility threshold of exceeding 10 percent of the first \$ 100,000 of annual income of a family plus exceeding 15 percent of the excess income over \$ 100,000 shall include, but are not limited to, the following:

1. Special education required as result of medical condition;
2. Elective cosmetic surgery/treatment; and
3. Modifications to vacation and secondary homes.

#### **§ 10:155-1.16 Administration of payments**

(a) The State Office shall oversee processing of payments from the Fund. Though in general payments shall be made directly to providers and vendors, consideration shall be given to making payments directly to families.

(b) Items in N.J.A.C. 10:155-1.14, Eligible health services, shall be considered for payments.

#### **§ 10:155-1.17 Appeal process**

(a) The following applies to the appeals:

1. Upon receipt of a determination by the State Office, an applicant who disputes that determination may appeal to the Catastrophic Illness in Children Relief Fund Commission by filing a written appeal to:

New Jersey State Department of Human Services  
Catastrophic Illness in Children Relief Fund Commission  
PO Box 0728  
Trenton, NJ 08625-0728  
Attn: Chairperson

2. Appeals must be received at the above address no later than 30 days from the date of notice of the determination made by the State Office. The Commission may waive the deadline for cause.

3. The written appeal shall include all reasons and grounds for disputing the determination made by the State Office and all proof and documentation in support of the appeal.

4. The Commission shall conduct such review and analysis as is necessary to reach a decision on the appeal. At its discretion, the Commission may direct a conference to be convened with the applicant, or may refer the matter to the Office of Administrative law pursuant to the Administrative Procedure Act, N.J.S.A. 52:14B-1 et seq., and the Uniform Administrative Procedure Rules, N.J.A.C. 1:1.

5. Except for appeals referred to the Office of Administrative Law, the Commission shall render a decision on the appeal within 180 days from the date of original receipt of the appeal. Appeals referred to the Office of Administrative Law shall be decided by the Commission within 45 days from the date of filing of the Initial Decision of the Administrative Law Judge, or at such later date as permitted by law.

6. A decision made by the Commission shall be final. It may be appealed to the Superior Court of New Jersey as permitted by court rules.

(b) Unless otherwise specifically ordered by the Commission, an applicant may not receive benefits from the Catastrophic Illness in Children Relief Fund while an appeal is pending at any level.

#### **§ 10:155-1.18 Special cases**

(a) Special cases shall be referred to the Commission for its review and consideration. Special cases shall include, but are not limited to, the following:

1. In special cases in which a family has more than one child with a catastrophic illness (as defined by expenses in excess of the 10 percent of the first \$ 100,000 of annual income of a family plus 15 percent of the excess income over \$ 100,000 threshold for each child), consideration shall be given to waiving the family responsibility as outlined in N.J.A.C. 10:155-1.2 for the other child/children given that the family would have already met the family responsibility for the first child in a State fiscal year.

2. For special hardship cases that come before the Commission during a batch cycle, after the standard disbursement guidelines have been applied to each case in the batch and sufficient monies remain in the Fund, consideration shall be given to waiving the standard disbursement guidelines (that is, the family responsibility and the cap as outlined in N.J.A.C. 10:155-1.2 and 1.7).

#### **§ 10:155-1.19 Confidentiality of information**

Information received pursuant to the duties required by the Act shall not be disclosed publicly in such a manner as to identify individuals unless special circumstances require such disclosure and the proper notice is served and parent or legal guardian's consent is given, as may be necessary for pending legal proceedings.

#### **§ 10:155-1.20 Recovery of Commission expenses**

(a) If a family receives assistance from the Fund for a child, in accordance with this chapter, and subsequently recovers damages or a financial award for the child's medical expenses, pursuant to a settlement or judgment in a legal action, the family shall reimburse the Fund for either:

1. The amount of assistance received from the Fund; or

2. The portion of assistance received for the injury, illness or condition covered by the damage or judgment, less the family's expenses of recovery.

(b) The Commission may negotiate or settle the recovery of such claims, for cause presented by the family to the Commission.



Examples of Catastrophic Illness in Children Relief Fund Program<sup>+</sup>

The examples below illustrate the extent to which the Fund would assist three families with different income levels.

## FAMILY #1 (with income of \$ 30,000)

Family income:.....\$30,000  
 Eligibility Standard (Exceeding 10% of income): .....3,000  
 Amount of Eligible Medical Expenses not Covered by Insurance:.....15,000  
 Family Responsibility (Exceeding 10% of Eligibility Standard):...300  
 Amount of Fund's Financial Assistance to Family: .....14,700  
 Amount for which Family remains responsible: .....300

## FAMILY #2 (with income of \$ 80,000)

Family income:.....\$80,000  
 Eligibility Standard (Exceeding 10% of income): .....8,000  
 Amount of Eligible Medical Expenses not Covered by Insurance:.....15,000  
 Family Responsibility (Exceeding 10% of Eligibility Standard):...800  
 Amount of Fund's Financial Assistance to Family: .....14,200  
 Amount for which Family remains responsible: .....800

## FAMILY #3 (with income of \$ 120,000)

Family income:.....\$ 120,000  
 Eligibility Standard:.....13,000  
     Exceeding 10% of the first \$ 100,000 or 10,000  
     Exceeding 15% of the excess over \$ 100,000 or 3,000  
 Amount of Eligible Medical Expenses not Covered by Insurance:.....15,000  
 Family Responsibility (Exceeding 10% of Eligibility Standard):...1,300  
 Amount of Fund's Financial Assistance to Family: .....13,700  
 Amount for which Family remains responsible: .....1,300

<sup>+</sup>Assuming: an annual \$ 100,000 cap; adequate monies available in Fund obviating need for additional restrictions and cost-sharing; and none of the cases are in the "special" category.